

4 July, 2008

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Ms Ellis,

Sydney Legacy provides the following submission to the Inquiry into "Better Support for Carers". Sydney Legacy is a voluntary organisation caring for the dependants of deceased Australian war veterans and service personnel killed on hazardous service or in training accidents. Sydney Legacy is one of 49 Legacy Clubs across Australia. The information being provided for the Committee's consideration has been obtained from the Sydney Legacy Widows' who are carers for people with chronic illness, disability and frailty and Community Service Workers who are employed by Sydney Legacy to advocate and provide information and links to funded services on behalf of Legacy dependants.

1. The Role And Contribution Of Carers In Society And How This Should Be Recognised.

- a) It is recommended that the role of the carer needs to be publicly recognized by systems that support the caring role. To recognize the contribution of carers' these systems need to include access to funded Government assistance, and access to funded transport, respite and suitable support services. The role of a carer needs to be publicly promoted in a way that promotes and recognizes the worth of carers as valued members of our society. Their role needs to be promoted as one that saves the community and governments considerable costs and adds to the quality of life for the person for whom they provide care.

2. The Barriers To Social And Economic Participation For Carers, With A Particular Focus On Helping Carers To Find And/Or Retain Employment.

- a) It is suggested that the carers role needs to be supported by Government through the provision of adequately funded service delivery, which needs to include; respite or in home support which enables the carer to stay in employment or to be able to engage regularly with social contact outside the home.

- b) What is required to provide carers the chance to stay in or enter the workforce is access to quality and affordable types of care, these supports are critical to work versus the carer role. In addition, employment opportunities such as working from home need to be offered by employers.
- c) The feedback received from Sydney Legacy widows' who are carers includes the following:
- Recognition that respite and services have a financial cost and this impacts on the person's pension and the carer's financial situation. Some services may not be accessed due to these costs.
 - There is often no time to seek employment or to be employed as the caring role is usually a 24 hours by seven days per week job.
 - The availability of, and access to, respite services to enable social interaction for the carer is extremely difficult to access, especially in rural areas.
 - It is important that a carer has a normal life as well as their role of carer. They need to have the ability and time to work or to be able to go out with their family. This is extremely difficult when they are carers.
 - As carers they cannot go out unless the person they are providing care for goes with them or respite is available. The need to plan everything in advance is constant, there can be no spontaneity in their lives.
 - Family problems – when disabilities take over the life of the family it is hard to keep the family together.
 - Services can let you down, they will organise a visit and then they don't turn up.
 - The country/rural areas have fewer services available and the needs there are different due to geographical isolation. If the person goes into care it may be that the person will be placed a long way from the carers home.
 - Employment – if the carer wanted to work they cannot because of the lack of care available and therefore there is no one to look after the person; it is too hard and they give up.

3. The Practical Measures Required To Better Support Carers, Including Key Priorities For Action.

The increase in life expectancy for a person with a disability and the fact that they now may outlive their parents/carer; combined with the expectation that people will continue to live in the community with informal and formal support has changed the need and type of services required for people with disabilities.

- a) It is recommended that the following key priorities need to be considered and actioned for carers':
- Waiting lists need to be kept by services to enable statistical data on unmet needs to be determined. These lists to be provided to Government to Highlight the unmet need.
 - The carer is to be actively involved and consulted in the service

delivery options available for them and the person they provide care for i.e. consultation on service delivery type.

- Services need to be provided in a holistic way to meet the needs of the carer and person receiving care as well as the person who is receiving care.
- The need to have a future plan for the person they provide care for without having to reach a crisis point, before accommodation options are made available.
- Financial recognition of the carers role.
- A coordinated health and community care system which is able to be responsive to the carers and the people they support.
- The regular provision of information on what services are available for them as carers and for the person they care for, which assists in the ability to obtain appropriate services.
- Case managers to assist the carer and the person who is receiving care to access appropriate services.
- Education of G.P's on the services that are available or provision to G.P's offices of pamphlets that people can access while at their health providers office.
- G.P's be encouraged to complete the necessary Taxi Subsidy Forms appropriately.
- The service system needs to be versatile in service delivery; Not the person fitting the service but the service meeting the person's need.

4. Strategies To Assist Carers To Access The Same Range Of Opportunities And Choices As The Wider Community, Including Strategies To Increase The Capacity For Carers To Make Choices Within Their Caring Roles, Transition Into And Out Of Caring, And Effectively Plan For The Future.

The suggested strategies are as follows:

- To provide an effective network of services providers, health professionals and support groups which collaborate and exist in a seamless support system for carers and the people they support.
- That carers' are able and encouraged to participate in the community and influence change in their lives and in the lives of people they support.
- Providing adequate information and support to assist carers' to make their own choices and opportunities which relate to their caring circumstances to include; health, employment, education, housing and wellbeing.
- To have a level of financial security and independence and a better work and life/carer balance.
- To overcome the concern of carers who ask "what will happen when I can no longer provide care" for the carer to be able to plan for their future and to assist the person they are caring for to plan for their future. This should include, without charge to the carer; the making of a Will, enduring power of attorney, enduring guardianship, power of attorney and access to respite and advice on succession planning which includes estate planning, Centerlink payments, trust arrangements and taxation.

I would like to say thank you for the opportunity to put forward these points for your Committees consideration on behalf of the Sydney Legacy Widows who are carers.

Mr. Andrew Condon
Chief Executive Officer
Sydney Legacy